

The Governor's Council on the Prevention of Developmental Disabilities

Annual Report for Fiscal Year 2022



The Governor's Council on the Prevention of Developmental Disabilities (the Council) and the Office for the Prevention of Developmental Disabilities (OPDD) were created by Public Law 1987, Chapter 5, and amended by Public Law 2000, Chapter 82. OPDD is based in the Department of Human Services' Division of Developmental Disabilities (DDD) and works with the Council and its Task Forces to pursue a common charge - the prevention of intellectual/developmental disabilities (IDDs) in the State of New Jersey. The Council serves as an advisory body to the OPDD and makes recommendations to the Commissioner of the Department of Human Services (DHS) regarding policies and programs to reduce or to prevent the incidence of IDDs in New Jersey.

The Council is comprised of 25 public members, who are appointed by the Governor. Members serve a three-year term. Additionally, the Council includes New Jersey State Commissioners, or their designees, of the Departments of Human Services, Community Affairs, Education, Health, and Environmental Protection, and the Secretary of State, serving as ex officio members. The Council reports annually to the Governor and the Legislature concerning the status of IDD prevention programs in the state, and administers two standing committees in the service of its mission; the Fetal Alcohol Spectrum Disorders (FASD) and Other Perinatal Addictions Task Force, and the Interagency Task Force on the Prevention of Lead Poisoning. Without compensation, public members of the Council imbue this work with a high level of intensity, expertise, and dedication.

Fiscal Year 2022 (FY 2022) Activities

With assistance from the OPDD, the Council met via online meeting platforms according to its quarterly schedule. This allowed the Council to continue its important work with funded projects commissioned by the OPDD and to embrace their role of working with partners to carry out its advisory mission to the OPDD and DHS. The Council and OPDD examined many IDD prevention programs throughout NJ. Efforts included online reviews of programs and policies, project meetings, and presentations to the Council by State and other institutions working in the field of prevention (see Appendix A). In FY 2022, the Council focused on the following activities:

Current Issues in the Prevention of Developmental Disabilities

The issues and concerns that can impact the proper development of a child are varied. The Council takes time, at every meeting, to review relevant child development impacts that become apparent in the work conducted by its members. The identification of current issues and possible actions to be taken regarding matters that can affect the development of children is of paramount concern to the Council. Several guest speakers presented information on matters affecting issues of health and support for pregnant women and child development. The Council reviewed the following topics to inform their recommendations to OPDD and other agencies:

- S-2879, the Federal "Advancing FASD Research, Prevention, and Services Act".
- Awareness of FASD in school-aged children.
- NJ State Health Assessment Data for childhood lead.

- New federal legislative support for lead poisoning prevention.
- Lead in drinking water.
- Community engagement strategies regarding lead and FASD awareness.
- Lead screening in the state of NJ.
- Community-centric approaches to lead reduction.
- Utilization of data among state entities to prevent lead poisoning.
- NJ Department of Environmental Protection (DEP)/Department of Health (DOH) Lead mapping project.
- DOH, Pregnancy Risk Assessment Monitoring System (PRAMS).
- Autism Screening and Intervention.
- Effects of race on maternal health.
- Maternal and infant health outcomes during COVID-19.
- Maternal Health Innovation Strategies.
- “Learn the Signs Act Early” developmental disability early identification initiative.
- NJ DOH, Birth Defects Registry (BDR) & Autism Reporting System.
- New Jersey’s Early Intervention system and its role in assisting children with elevated blood lead levels.
- Office for the Prevention of Developmental Disabilities Requests for Letters of Interest and grant funding.
- As required by the New Jersey State Ethics Commission, Council members completed Special State Officer Ethics Training.
- Impact of the legalization of cannabis on maternal and child health in NJ.
 - The Council made recommendations to the Cannabis Regulatory Commission addressing the need to create a cannabis use and pregnancy warning poster; and require warning labels to be placed on all cannabis products stating that the products are not intended for use by minors or individuals who are pregnant or breastfeeding or plan to be pregnant.

New Jersey Task Force on Fetal Alcohol Spectrum Disorders and Other Perinatal Addictions (FASD Task Force)

Fetal Alcohol Spectrum Disorder (FASD), a developmental disability resulting from fetal alcohol exposure during pregnancy, is 100% preventable. The mission of the New Jersey Task Force on Fetal Alcohol Spectrum Disorders and other Perinatal Addictions (FASDTF) is to: provide education regarding the causal relationship between the exposure to alcohol and other substances during pregnancy and the incidence of Fetal Alcohol Spectrum Disorders (FASD); and promote effective, life-long interventions for individuals affected by prenatal exposure to alcohol and other substances.

FASDTF members met via online platforms in July, October and December 2021 as well as during January and March 2022.

The members of the FASDTF work on the front lines of FASD prevention. They engage with community organizations and policy professionals regarding news, research, best practices, and programs, locally and nationally, related to FASD. The FASDTF focused on increasing awareness in New Jersey about FASD and perinatal substance use disorders among the public and healthcare professionals. Additionally, FASDTF members engaged in vigorous discussions pertaining to cannabis legalization, its increased usage in NJ, and its potential impact on fetal development.

During FY 2022, the work accomplished by the FASDTF included the following issues and initiatives, which were determined to be priority work items by the FASDTF:

- As part of FASD Awareness Day/Month, the FASDTF worked with its partners to create awareness of FASD and maternal health in general. Some of these activities targeted schools and university settings.
- Website promotion activities continued, including planning around updates and regular content reviews as well as additional promotion by NJ's maternal/child health consortia.
- NJ Maternal/Child Health Consortia partnered with FASDTF on FASD awareness activities, which included:
 - In-person health fairs;
 - In-person school presentations;
 - In-person hospital presentations;
 - Social media activities;
 - Office hours regarding pregnancy and substance use;
 - Non-profit agency partner trainings; and
 - Development of a 30-second FASD awareness video that is shown in doctor's waiting rooms.
- FASDTF reviewed and discussed the Federal FASD Respect Act (Advancing FASD Research, Services, and Prevention Act).
- Members of the FASDTF participated in FASD United Policy Forums.
- FASDTF members examined methods to create awareness of the potential danger of the use of cannabis products while pregnant, given that the legalization of recreational use cannabis in New Jersey was a leading topic of review and discussion during FY 2022. FASDTF members provided information and suggested language for the Council to utilize for policy recommendations submitted to the Cannabis Regulatory Commission. The FASDTF will continue to monitor this issue.

Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force)

Lead is one of the leading preventable environmental health threats to New Jersey's children. Due to the state's extensive industrial heritage and high proportion of pre-1978 housing, lead continues to be an important I/DD prevention issue. Despite the ban on residential use in 1978,

lead continues to affect the lives of families. Our country's aging water delivery infrastructure, in addition to the hazards of lead paint, motivate the members of the Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force) to reduce lead's dangerous footprint in NJ.

The immediate impact of lead can be profound, and it may also have long-term multigenerational effects. New Jersey is the most densely populated state, and its residents are at higher risk for elevated blood lead levels because of substantial amounts of lead contamination.

The mission of the Lead Task Force is to: reduce childhood lead poisoning; promote lead-safe and healthy housing; support education and blood lead screening; and support interagency collaboration.

Lead Task Force members include representatives from state agencies charged with addressing the health and environmental problems caused by exposure to lead. The Departments of Human Services, Community Affairs, Environmental Protection, and Health are represented on the Task Force. The U.S. Environmental Protection Agency, Rutgers University, and many local public health, housing, and social service agencies also participate on the Lead Task Force.

In FY 2022, the Lead Task Force met online in September and December 2021 and during March and June 2022. The Lead Task Force reviewed and made recommendations pertaining to current lead issues impacting the State of New Jersey during each meeting. The following issues and items received attention from the Lead Task Force during FY 2022:

- The Lead Task Force received regular updates pertaining to lead initiatives from DOH and Department of Community Affairs.
- The Municipal Lead Abatement Program, administered by the Department of Community Affairs, provided funding to 13 municipalities (Bridgeton, East Orange, Jersey City, Edison, Passaic, Paterson, Elizabeth, Newark, Woodbridge, Plainfield, Irvington, Trenton, and Atlantic City) for lead abatement work.
- Sustainable New Jersey's work to promote Municipal Action to Reduce Lead Exposure was reviewed and discussed.
- New Jersey Future's "Lead Free NJ" aims to ensure that children are free from lead poisoning. This collaborative model includes community tables to promote the voices of affected populations in policy recommendations.
- The Lead Task Force received updates from the Northern, Central and Southern Lead Coalitions in order to learn about new and ongoing lead poisoning prevention initiatives around the state of NJ.
- National Childhood Lead Poisoning Prevention Week was observed from October 25-29, 2021. Lead Task Force members participated in activities throughout the state of NJ. Some of these activities included:
 - Coalition-hosted virtual events including:
 - Children's Keep Me Lead Free Workshop via Zoom.

- Facebook En Vivo, a Lead Presentation for Spanish-speaking parents.
- Instagram Live, Q&A about lead.
- A virtual Lead Prevention Resource Fair was held via Zoom Event at National Park Elementary School in Gloucester County which included a lead screening pilot program, and offered lead testing for children.
- The Rinsey *Raccoon* handwashing e-book was promoted by members.

Lead Task Force members continued small group work focusing on:

- The screening of children, including reporting of data and enrollment of children with elevated blood lead levels in Early Intervention, which included the review of the new lead law (S-1147/A-1372) requiring new training for remediation and abatement; new agency partnerships; establishment of best practices and guidelines; and understanding enforcement responsibilities.
- The utility of DEP's new Potential Lead Exposure Mapping tool (PLEM) and recommended that the tool could be improved upon by layering maps and adding more filters.
- In October 2021, the CDC lowered the blood lead reference value, the threshold for public health intervention, from 5.0 to 3.5 $\mu\text{g}/\text{dL}$. The DOH is reviewing and revising the threshold in New Jersey in accordance with this change, and anticipates an additional ~4,000 identified cases due to the lowering of the threshold.
- The challenge of helping parents and physicians to recognize the importance of lead screening.
- Ensuring that resources are invested in inspections, remediation & abatement, case management, and relocations if the state invests more resources towards screening.

The Data Reporting small group discussions focused on the following issues:

- Impacts of and considerations for the new lead law (S-1147/A-1372) in NJ, including expansion of public education, home inspections and increased home remediation workloads.
- As pandemic restrictions have eased, increased school attendance has resulted in greater detections of lead due to more blood lead screening opportunities.
- Discussion of PLEM included requests for more mapped information on water lines, use of the maps as supporting evidence for groups seeking grant funding, and using map data for program and staffing costs. Rochester, NY and Cleveland, OH were recommended as examples of cities with model mapping tools to be examined.
- Opportunities for cross collaboration: Sustainable Jersey activity, such as the Healthy Homes initiative, can serve as support for municipalities as the DEP/DOH's Healthy Community Planning NJ program rolls out. The program includes indicators for lead paint and housing and health outcomes around childhood lead exposure. Sustainable Jersey is also a part of Lead Free NJ, an excellent resource for sharing information about lead exposure and mitigation. DEP is also working/coordinating with the Department of Education (DOE) and Department of Children and Families (DCF) around water testing and data management.

The Early Intervention small group discussions included the following:

- Impact of the new lead law (S-1147/A-1372).
- COVID-19 pandemic as a barrier for lead testing and outreach, and ways to overcome the challenges, such as a pilot program with Cumberland County collaborating with pediatricians to promote and provide lead testing in their offices.
- Resource sharing, including the idea of the PLEM tool being shared with Sustainable Jersey.
- The importance of education for follow up with venous, not capillary, testing with providers.
- Successful outreach models through preschools and daycares, such as the Virtua Mobile Van in South Jersey, which conducted successful outreach and hosted an event to provide lead education and lead screenings at a designated school.

The Lead Task Force heard from speakers on subjects intended to assist them with their work. Speakers included:

- Lead Safe Certificate: Ben Haygood, Isles Inc.
- Potential Lead Exposure Mapping (PLEM) – Housing in New Jersey: Barbara Goun (DOH), Christine Schell (DEP) and Steve Anderson (DEP).
- Promoting Municipal Action to Reduce Lead Exposure: Melanie McDermott, Sustainable New Jersey.
- Lead-Free NJ: A Community-Centric Approach to Lead Reduction: Peter Chen, New Jersey Future.

Office for the Prevention of Developmental Disabilities Grant Funding

One of the OPDD's tasks is implementing, monitoring, and evaluating community prevention programs that receive support from its annual state appropriation. The OPDD funds agency projects that are intended to prevent IDD. FY 2023 will start a new three-year funding cycle. The OPDD Request for Proposal (RFP) subcommittee played a critical role in the selection of new projects to fund starting in July 2022. This subcommittee reported to DDD regarding the strength of proposals that were submitted in response to the OPDD Request for Letters of Interest (RLI). Subcommittee member expertise is an important component of the proposal review process and assists DDD in recognizing best practices and important issues influencing the prevention of developmental disabilities.

New Projects Funded During Fiscal Years 2023–2025

Partnership for Maternal and Child Health of Northern NJ (PMCHNNJ)

Award: \$185,000 per year

The PMCHNNJ will implement the Smart Choices for Healthy Living Project. FASD United (formerly NOFAS) developed a K-12 Fetal Alcohol Spectrum Disorder (FASD) Education and Prevention curriculum. The Smart Choices for Healthy Living Project will utilize this curriculum with K-12 youths that live in Bergen, Essex, Hudson, Morris, Passaic, Sussex and Warren counties in order to prevent IDDs by reducing the incidence of FASD. PMCHNNJ will also

provide screening and early intervention education to school nurses and FASD prevention education to college students.

New Jersey Chapter of the American Academy of Pediatrics (NJ AAP)

Award: \$185,000 per year

The NJ AAP will implement the Childhood Lead Poisoning Education ECHO project. This program intends to educate primary care clinicians and community stakeholders about the importance of prevention, early identification and referral of children with elevated blood lead levels. The program will also educate pediatric providers about the Department of Community Affairs (DCA) remediation program so that they can refer families to receive free home inspections to identify potential sources of lead. The two-tiered program will utilize the Project ECHO model of virtual case based bi-directional education to ensure that a wide audience of diverse clinical and community stakeholders can participate.

Parent Advocacy Network (SPAN)

Award: \$185,000 per year

Leaders Empowered as Advocates with Dignity (LEAD) is a new project to be implemented by SPAN. It will focus on maternal, paternal and children's health and mental health by providing leadership training and education, and community engagement for women and men of childbearing age to prevent IDD's, specifically Fetal Alcohol Syndrome/Fetal Alcohol Spectrum Disorder (FAS/FASD). The LEAD project will address the social determinants of health including poverty, language barriers, ACEs, societal and environmental stress, access to service systems, immigration, language barriers, and others that influence issues such as smoking, substance use, and nutrition.

Ongoing Projects Funded in FY 2022

FY 2022 was the third year of a three-year funding cycle. Projects receiving their final year of funding were as follows.

Parent Advocacy Network (SPAN) - \$184,975 per year

The overarching goal of *Empowering Women in Community Leadership for Healthier Families* project is to enhance state and community efforts to reduce the risk of preventable IDD's, specifically fetal alcohol syndrome (FAS)/fetal alcohol spectrum disorders (FASD) and those caused by lead poisoning. This will be accomplished by: a) providing peer support groups for diverse women of childbearing age, particularly those from underserved communities; and b) training women of childbearing age to be peer leaders who educate and advocate in their communities to reduce the risk of preventable IDD's.

Partnership for Maternal & Child Health of Northern NJ (PMCHNNJ) - \$185,000 per year.

The Smart Choices for a Healthy Life project utilizes the National Organization on Fetal Alcohol Syndrome (NOFAS) (now FASD United) K-12 Education and Prevention Curriculum in schools, after school programs, CBOs, and school districts serving target municipalities. The curriculum addresses many important topics for school-aged students beyond FASD and what can happen to human development when a pregnant woman drinks alcohol. It teaches about the overall effects that alcohol can have on the body, why some people who drink alcohol become addicted while others do not, that at any age each individual has strengths and weaknesses, and that it matters how you treat people.

Rutgers School of Public Health - \$185,000 per year

The focus of this project is young children, attending a large pediatric practice, whose parents report an early delay in social communication development. These children may be at greater risk of Autism Spectrum Disorder (ASD). Children's social communication development will be evaluated through use of the Psychological Development Questionnaire for Toddlers (PDQ-1) to be completed by parents with children receiving pediatric care from the Rutgers—New Jersey Medical School (NJMS) Pediatric Continuity Care Clinic (PCCC). The PCCC is a medical anchor of Central Ward Newark. The PCCC serves as the community's first line of expertise with regard to detection of learning and developmental problems and in assisting families with special needs children. The population to be served by this project are approximately 6,000 to 7,000 Newark-residing children between the ages of 18 and 24 months and their parents, served by the PCCC, in 2020 and 2021. Most of the screened children will be in the highest risk group for late evaluation, late diagnosis and late receipt of interventions. This project is intended to have a high impact on this population of children with ASD, who, on receiving timely autism screening, will go on to be served by an Early Intervention Program (EIP).

Appendix A

Presentations to the Governor's Council on the Prevention of Developmental Disabilities

9/23/2020

- Ethics Training for Special State Officers
Kya Saunders, Legal Specialist, DHS

12/15/2021

- Maternal Health in NJ
Gloria Bachmann, MD & Pamela Brug, MD

3/23/2022

- Learn the Signs Act Early
Deepa Srinivasavaradan & Caroline Coffield, Ph.D.
- DOH Birth Defects & Autism Reporting System
Lisa Stout, BSN, RN

6/22/2022

- Rutgers ASD Screening Project
Walter Zahorodny, Ph.D.

Appendix B

Governor's Council on the Prevention of Developmental Disabilities FY 2022 Membership

State of New Jersey Government Representatives

Adam Bucon, LSW	Department of Human Services
Lisa Stout, BSN, RN	Department of Health
Kenneth Richards	Department of Education
Jennifer Underwood	Department of Community Affairs
Gloria Post, Ph.D., DABT	Department of Environmental Protection
Rowena Madden	Department of State

Public Members

1. Dorothy Angelini, MSN
2. Jeananne Arnone, RN, BS
3. Caroline Coffield, Ph.D.
4. Forest Elliot, M.A., LDTC
5. Carol Ann Hogan, M.S. Ed.
6. William Holloway, Ph.D.
7. Martin Johnson
8. George Lambert, MD
9. Barbara May, RN, MPH
10. Michael McCormack, Ph.D., FACMG
11. Judith Morales, MSW, LCSW
12. Munir Nazir, MD
13. Beatriz Oesterheld
14. Daniel Ranieri
15. Marlene Schwebel, JD, APN
16. Alyce M. Thomas, RD
17. Yvonne Wesley, RN, Ph.D.
18. Thomas Westover, MD
19. Jean Wiegner, CSNA
20. Leon Zimmerman
21. Ilise Zimmerman, MS

Staff

Jonathan Sabin, LSW
Director, Office for the Prevention of Developmental Disabilities